Reimagine Today Podcast

NDIS Back To Basics

Episode 01 - Psychosocial Disabilities & Cultural Barriers

(Transcript) [22 minutes and 58 seconds]

Charles Manila, Host Intro

Welcome to the reimagine today podcast where we talk to people about their stories and experiences of the NDIS. I'm Charles Manila, the host for the reimagine today podcast. And in this episode, I'll be joined by Sophie Duterte, from the Centre for Culture, Ethnicity and Health and Mohamed Umar, a support coordinator from Neami National and an NDIS participant.

This podcast explores the lives of people who experience psychosocial disability, family and carers, workers and professionals and their personal stories regarding accessing and understanding the NDIS, with a particular focus on the experiences of people from culturally and linguistically diverse backgrounds. We hope their stories will shed light on the wider social issues facing a diverse array of people wanting to access mental health and disability services.

This episode is part of a multi episodic series called NDIS Back to Basics we will be discussing the complexities of the key language used when discussing the NDIS, and some of the cultural barriers individuals may face regarding access and understanding the NDIS.

Please note that this episode and the series as a whole involves discussions of sensitive topics that can be distressing or uncomfortable. We advise that you listen to this somewhere you feel safe and if you are affected by the content, pause the recording and take a break, and consider speaking to someone you trust, or calling a helpline for support. Thank you.

Charles Manila, Introducing the Guests

I am joined by Sophie and Mo, but feel free to introduce yourselves.

Sophie Duterte, Centre for Culture, Ethnicity and Health

My name is Sophie Duterte, I work for the Centre for Culture, Ethnicity and Health which is part of North Richmond Community Health, and more specifically, I work on an NDIS project where I train interpreters and bicultural workers in understanding the NDIS and being able to explain or interpret NDIS terminologies in very simple ways.

Mohamed Umar, Neami National, NDIS participant

My name is Mohamed Umar, I am a support coordinator at Neami National and I'm also an NDIS participant.

Charles Manila, Acknowledgement of Country and Lived Experience

Before we begin, I acknowledge the Traditional Owners of the land on which we are meeting. I pay my respects to their Elders, past, present and emerging, and the Aboriginal Elders of other communities who may be here today.

I would also like to acknowledge all people who have personal experience of mental illness, whether as consumers, carers or workers. Your voices, insights and experiences are invaluable and important. Keep fighting to be heard!

Psychosocial Disabilities

Charles Manila

It goes without saying, if we were ever to tackle the complexities of the NDIS language, it would be remiss to forget about possibly the most important key terminology involved. "Psychosocial Disability." Sophie, what exactly is Psychosocial Disability and how does that relate to mental health?

Sophie Duterte

Psychosocial is a word that many people don't understand and that's partly because it was not so much created by the NDIS but certainly popularised by the NDIS and it's become a term that's used very often. And because I work with interpreters, I'm always very conscious that the person on the other side is someone who doesn't speak English or has limited English but also might have limited literacy or education and so even if a word exists in their language it doesn't mean they'll understand it. And psychosocial is a case in point, it really needs to be explained. The way I explain it in my training is to say, "it's about the way you interact with the world, you engage with the world". So the example I give is you can have anxiety and manage it and whether it's through medication or some personal techniques, you go to work, you have a social life, people around you might not be aware that you have anxiety. Or you can have anxiety where you can't leave your house, you're scared of crowds, you're scared of being in a closed space, you have claustrophobia, the anxiety actually stops you from engaging with the world around you. That is when it becomes a psychosocial disability. That's how I explain it.

Charles Manila

Mo, what was the first thought you had when you heard that term "psychosocial disability?"

Mohamed Umar

I have probably heard that far more often in the past couple of years and that's obviously due to the NDIS. But before that, I do believe that when I came across it, I just assumed that it was a word that you would just see in the dictionary, literal kind of meaning and understanding from

just the scientific point of it and it's not something that is necessarily used in everyday life. But it has kind of been interesting because for me mental health issues is something that people are more familiar with in terms of understanding and from my experiences of someone from a CALD background and who's also been involved in the welfare sector for the past 11-12 years, I've always encountered a lot of unexpected reactions from people whenever mental health was mentioned simply because mental health if it is translated or interpreted in different languages in to some people it means something that's completely different, which basically means something about health issues in terms of your mental state. I know that for me personally, that was something that I have experienced initially, it came from my original understanding of wellbeing as not an issue. Wellbeing is an issue where you feel like you're functioning as a human being, as long as you're functioning that's fine. But then when you come across the challenges that commit people to be living in a life that is full of struggle, challenges and a lot of issues - that is a life that you're used to and your life does not necessarily mean that you are going through anything or you don't really think there is a different aspect of life. So, you accept that is a point blank. So the idea of a psychosocial disability is kind of interesting and from my perspective and I know that people that are not involved in the clinical side of things in terms of understanding mental health especially from CALD communities that it is something they completely don't understand and they are completely aren't able to talk about it, in terms of their health issues especially if it's about their mental health.

Charles Manila

Sophie, anything to add to that?

Sophie Duterte

Just that, I think following up on Mo when you talk about struggles and people's struggles, I think that's such a good point because it must be hard I imagine for some people to separate the struggles of their life from the struggles that is caused by their disability, especially if it's a mental health issue. It's just something that occurs to me when I'm listening to you that people might experience struggles and they might associate them with external factors rather than identifying that it is something that's related to mental health.

Mohamed Umar

Yes, I do agree. I think one of the probably most prevalent issue that I've noticed in the CALD community especially people that have recently arrived from war-torn countries, the idea they are going through so much trauma and not really understanding what that really meant for them. I mean PTSD is something very, very prevalent and I see that everywhere and people just "well it's okay, that's just life and you move on from it." But you also see the negative impacts of these traumas and these issues people are going through every day and they do not have the capacity to deal with it and they do not know the importance of dealing with it. And they do not know [how] to address the issues that are kind of side effects of some of those issues. It's kind of interesting, because it's almost like trying to tell somebody about something that they know

nothing about. The idea that people are expected to understand their mental health when they don't know it themselves what mental health is. Eventually, it comes down to knowledge, it comes down to education, it comes down to our awareness. And that's something that is probably the most lacking in terms of the frontline of welfare and welfare organisation and welfare system. And I'm speaking especially from the CALD community here.

CALD Community Perspectives

Charles Manila

One of the things I've heard from what you were saying was the concept of trauma, has that been difficult to explain to CALD communities in your experience?

Sophie Duterte

I'd rather let Mo speak about that because it's not something I have huge experience in, but certainly listening to you Mo it's reminding of the time I worked with asylum seekers and newly arrived people on refugee visas. People would say "I'm depressed, because I don't have a job. I don't have a proper house and then they would get a job, and they would get proper accommodation and they would get all these external things and they would still be sad and they would be like "why am I still sad? Because I've got all those things I've wanted and especially if someone got a permanent visa for instance and they thought it would be the end of all their problems and it wasn't. So it's what you're saying about, if people don't know there is such a thing as a problem with mental health and mental health issues, then when they are not happy, just to put it in very simple terms, they don't quite know what the cause of it could be.

Charles Manila

Any thoughts on that Mo?

Mohamed Umar

I agree 100%. I am speaking of my experiences for example. I came over when I was in my late teens and my understanding of the world was just my experiences. But I came here with huge expectations and you know, the idea that life is going to completely change for you and you don't have to deal with whatever most people are trying to get away from when they try to settle in a new country. The concept of psychosocial disability being a socially generated disability which basically means deficiencies that occur due to issues within the social aspect of a human being. I mean that would categorically put people from CALD backgrounds in that space. I mean, they have mostly left an environment where there was wars, there was famine, there was hunger there was a lot of issues to go through all of that. I mean to just get to the place where you finally are, so people never really understand what it is that people have went through to get into that position. I did eventually realise that I am here now, my life has changed and in terms of my needs as a human being, my needs have completely changed because I understood that my needs initially were about the necessities of life. You're talking about food, shelter and security and once you get that, then you're socially isolated just to begin with, you have no sense of community and you also realise that our natural tendencies of happy life are not

necessarily just mean finding the basic things. You end up being more mentally exhausted, mentally stressed, mentally isolated then you've ever been before. And that for me was a very unexpected experience and it wasn't just for me. There was a big family that came here with me. And it was something that was common, especially around young people that were in their late teens and even in the upper early twenties so I could understand that all of a sudden people were just going "so now what am I supposed to do?" And then you also have deal with the issues that you've been through that you haven't really addressed. You just assumed that was just going to be something that would go away. It took me awhile to kind of understand what it truly meant because you naturally try to address your needs in terms of what you feel like you need with anything that you find possibly as a pain reliever. People have different coping mechanisms, so people will have to fill that gap with something because the services aren't there to implement those kinds of supports in the first place. And eventually one of the most common side effects that I've seen is that people start to rebel because all of a sudden those people that are in that position actually get a sense of that they're not actually wanted here, they're not part of this community and all of a sudden you're in limbo. And the usually next step for young people is to go in wrong pathways simply because there's no right pathway available. And when you have someone against the wall that's dealing with so much, you can never tell what would tick them off or put them in far more worse situation because they don't simply at that point believe in their life could get any worse.

Disparities of Understandings and Building Relationships

Charles Manila

I think from our discussion so far, what's clear is there is a massive disparity between commonly used terminologies when talking about the NDIS and people's understanding of it, especially for people with CALD backgrounds, it's a massive barrier. Also, it feels like that there is an expectation for people of different cultures to immediately get on board with understanding it quite quickly and without regarding the possible issues that may arise from it. Drawing from what you were saying Mo, concepts like happiness and necessities can be so different. Would you agree with that sentiment? And have you encountered issues like this with the people you were working for and with?

Mohamed Umar

Definitely, I mean that is something very, very prevalent in terms of the issues people are going through and the organisations that are on the front of dealing with some of these issues that are actually struggling and they know it but it's impossible to deal with it with the perspective that services that are dealing with it now which is almost a band-aid for something that's far more significant to people. I mean the idea that a person of a migrant background to have a relationship with somebody to talk about the basic daily lives and issues to complete strangers, something that is not very common. It takes time, it takes effort to build up a relationship for people to be able to be in that position to feel like they are confident enough to share issues that are naturally kept under the closet for a lot of communities simply because there is a sense of

stigma in terms of people dealing with a mental health issue. There's a stigma of people even talking about their struggles. There's a sense of expected inability for individuals to deal with things just as they come instead of dwell and talking about issues and trying to deal with issues. That is different for a lot of people, but for my experience and for what I have seen, especially within CALD communities, especially people that came from war-torn countries, people that have come from a lot of trauma backgrounds, people that have come from countries where the education system, the life standard, their everyday life are challenging as a part of life. The sense of there's no relatability in terms of the person you're sharing your story with. I think that's something that's really, really important that people really forget, representation matters, in terms of seeing somebody that you feel like you have something in common with, when you're having a conversation with someone and you figure out for example - one particular thing we have in common whether it's sport or it's movies or it's art, you naturally notice your sense of closeness immediately changes and it's just natural and people think "Okay, now I feel like I can talk to this person, it's how friendships are formed, that's how close life relationships are formed. And when you have people that feel like not that they can't relate to you but they feel like you will not be able to relate to them, that puts them in a place where they feel like "there's no point in me talking about things that I feel uncomfortable talking about myself at times to somebody that they are not in a position, or they have never experienced themselves.

Charles Manila, Outro

This was part one of a multi-part episodic series for the Reimagine today podcasts called NDIS Back to Basics, where I sat down and had a conversation with Sophie Duterte from the Centre of Culture, Ethnicity and Health, and Mohamed Umar, a support coordinator from Neami National and an NDIS participant. Join us next time, when we discuss about Mohamed's experience as a support coordinator, the importance of goals and aspirations, and what it feels like applying for the NDIS.

I'm Charles Manila, the host for the Reimagine today podcast, signing off and remember, your voice matters, so keep the conversation going.

Safety Message

This episode contained discussions of psychological distress and trauma. If, after listening to this episode, you need support, please reach out and talk to someone you trust. You can also reach out to the following services: call Beyond Blue on 1300 224 636 for brief counselling and referrals. Or call Lifeline at 13 11 14. If you need an interpreter, you can ask these services for one. If it is an emergency, call 000. Take care and stay safe.